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# Preventing the Selection of "Deaf Embryos" Under the Human Fertilisation and Embryology Act 2008

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## **Preventing the selection of “deaf embryos” under the Human Fertilisation and Embryology Act 2008: problematizing disability?**

### **Abstract**

Section 14(4) of the Human Fertilisation and Embryology Act 2008 imposes – within the general licensing conditions listed in the Human Fertilisation and Embryology Act 1990 – a prohibition to prevent the selection and implantation of embryos for the purpose of creating a child who will be born with a “serious disability.” This article offers a perspective that demonstrates the problematic nature of the consultation, review, and legislative reform process surrounding s 14(4). The term “serious disability” is not defined within the legislation, but we highlight the fact that s 14(4) was passed with the case of selecting deaf children in mind. We consider some of the literature on the topic of disability and deafness, which, we think, casts some doubt on the view that deafness is a “serious disability.” The main position we advance is that the lack of serious engagement with alternative viewpoints during the legislative process was unsatisfactory. We argue that the contested nature of deafness necessitates a more robust consultation process and a clearer explanation and defence of the normative position that underpins s 14(4).

### **Keywords**

- **Human Fertilisation and Embryology Act 2008,**
- **deaf,**
- **deafness,**
- **disability**

## Introduction

As outlined within the other papers in this special edition, the Human Fertilisation and Embryology Act 2008 (“the 2008 Act”) reforms the original statutory framework found within the Human Fertilisation and Embryology Act 1990 (“the 1990 Act”). Section 14(4) of the 2008 Act implements a new prohibition within the 1990 Act. It mandates that licensed fertility clinics must not “prefer” embryos or gamete donors known to have a genetic abnormality that is likely to result in the birth of a child with a “serious physical or mental disability” or a “serious illness.” Although the term “serious disability” is not defined anywhere within the legislative framework, Paragraph 110 of the original version of the Explanatory Notes to the Human Fertilisation and Embryology Bill made it clear that the provision was intended to apply to the deliberate selection of embryos, or gamete donors, for deafness:

Clause 14(4) ... make[s] it a condition of a treatment licence that embryos that are known to have an abnormality ... are not to be preferred to embryos not known to have such an abnormality. The same restriction is also applied to the selection of persons as gamete or embryo donors. Outside the UK, the positive selection of deaf donors in order deliberately to result in a deaf child has been reported. This provision would prevent selection for a similar purpose.

Subsequently, the reference to deafness was removed from the Explanatory Notes (Emery, Middleton, and Turner 2010, 165). However, as will be outlined in this paper, the explicit reference to deafness within the original explanation of the scope of s 14(4) implies that Parliament had formed the view that deafness should be classified as a *serious* disability, and more controversially, one which should be avoided during reproductive decision-making. For reasons outlined below, this is problematic, not least because of the Government's lack of engagement and consultation concerning the impact of the provision.

The reference to the positive selection of deaf donors in the original version of the Explanatory Notes is most likely a reference to the decision of a lesbian couple in the USA who had succeeded in their desire to have a “disabled” child. Candy McCullough and Sharon Duchesneau, both Deaf, selected a sperm donor with five generations of deafness in his family, to increase their chances of conceiving a Deaf child. Their son, Gauvin, was born deaf (Sanghavi 2006). It is important to understand the motivation that may be underpinning such a decision. Far from regarding deafness as a disability, many Deaf people who have

been deaf since birth view deafness in a positive light (Lane 2002, 369). As we discuss below, to them, the Deaf world is a different but equally valuable culture.

The question of whether it is right to prevent the conception of deaf children by means of assisted reproductive technologies is complex. The scholarly literature on this issue considers a variety of viewpoints and ethical or philosophical perspectives in an attempt to inform the debate. These perspectives include, for example; disability analyses (Lillehammer 2005; Glover 2006; Harris 2007; Shaw 2008; Wilkinson 2010), and most commonly, a child welfare perspective, thus addressing the notion that a child is “harmed” by being purposely selected as deaf (Gavaghan 2007a, 2007b; Taylor 2010; Wilkinson 2010; Fahmy 2011).

Some of the latter literature has considered the existential argument based on the view that the only alternative for children purposely conceived in this way is not the opportunity to be born with the ability to hear, but to never exist at all (Gavaghan 2007b, 75; Wilkinson 2010; Fahmy 2011). For those who oppose the prohibition, the existential arguments are significant. For example, this reasoning underpins the view that there is a significant ethical distinction between selecting a child who will be born deaf, and deafening a hearing child (Häyry 2004).

Given that there is a large amount of literature already published on these viewpoints, we do not seek to add them. Instead, we seek to provide a perspective that demonstrates the problematic nature of the consultation, review, and legislative reform process surrounding s 14(4). We consider some of the literature on the topic of disability and deafness, which, we think, casts some doubt on the view that deafness is a “serious disability.” As discussed below, the main position that we advance in this paper is that the lack of serious engagement with alternative viewpoints during the legislative process was unsatisfactory. We argue that the contested nature of deafness necessitates a more robust consultation process and a clearer explanation and defence of the normative position that underpins s 14(4).

## **The impact of s 14(4) and the legislative process**

### **The position prior to the 2008 Act**

Prior to the 2008 Act, the UK legislative framework did not directly prohibit the “screening in” of particular genetic conditions or “disabilities.” Pre-implantation genetic diagnosis (PGD) practices were regulated in accordance with the general licensing conditions outlined under the legislative framework, and by the policy of the Human Fertilisation and Embryology Authority (HFEA) as issued within the Code of Practice.

According to the general licensing conditions within the legislation, the HFEA's discretion to issue treatment licenses extended to authorizing practices that are intended to ensure that embryos are in a “suitable” condition to be placed in a woman (Human Fertilisation and Embryology Act 1990, Schedule 2, Paragraph 1(1)(d)). The meaning of “suitable” in this context has been given a broad interpretation, which has been held to extend to determining the tissue-type of an embryo (see *R (on the application of Quintavalle) v Human Fertilisation and Embryology Authority* (2005) 2 All ER 555).

This broad interpretation, together with the fact that the legislation did not expressly prohibit the implantation of an embryo with an abnormality, meant that the HFEA retained the discretion to determine whether a license for this purpose could be authorized. The question of whether a license for “screening in” deafness would have been authorized by the HFEA prior to the implementation of s 14(4), is uncertain. It has been noted, however, that the HFEA adopted a very restrictive approach to PGD: “clinics were only licensed to ‘screen-out’ embryos with a ‘significant risk of serious genetic conditions’” (Taylor 2010, 74). Furthermore, it has also been similarly observed that because of the obligation imposed under s 13(5) of the legislative framework – one of the general licensing conditions contained within the legislation that requires those providing treatment services to make an assessment in relation to the welfare of any child who will be born as a result of such a procedure – the use of PGD for screening in a “disability” was likely to be prohibited if it was considered to be “detrimental to the welfare of the child” (Taylor 2010, 74) (for an analysis of the reforms to the welfare clause under the 2008 Act, see the paper by Julie McCandless, which is also in this collection).

Irrespective of whether welfare concerns or other grounds could have been cited for the grant or refusal of a license to select in favor of deafness (if such an application had ever been made), the previous regulatory position would have left the HFEA with the discretion to make the decision. And due to the novel nature of PGD in this context, the HFEA's Ethics Committee (or other appropriate committee, such as the Licensing Committee) may have considered the range of ethical issues and viewpoints underpinning the motivation to select in favor of deafness. Of course, s 14(4) of the 2008 Act has now removed the HFEA's discretion to grant a license to select for “serious” disabilities.

This raises a question of interpretation. Is deafness to be regarded as a serious or non-serious disability for the purposes of the legislation? Although in 2008, explicit references to deafness were removed from the explanatory note for clause 14(4), it is extremely doubtful

that this opens up the possibility for debate over whether or not deafness falls within or outside the scope of the term “serious disability.” A letter issued by the Department of Health in 2008 confirms that notwithstanding the deletion of references to deafness, the Government's position remained that it endorsed the use of PGD to avoid inherited deafness on the grounds that deafness is a “serious genetic condition.” Furthermore, the Government did not regard the use of PGD to select for deafness as an appropriate use of the technology (Department of Health 2008). Although s 14(4) has, therefore, achieved a degree of legal certainty in relation to selecting in favor of deafness, we acknowledge that the adoption of the term “serious disability” without definition may pose further problems in the future. Thus, further interpretational difficulties may be faced in the event that there is a need to consider whether other types of “disability” (beyond the case of deafness) are to be regarded as “serious.” The following section questions whether the difficult issues raised by categorizing deafness as a “serious disability” were addressed adequately during the drafting of the 2008 Act.

### **The legislative reform process**

In December 2006, the Department of Health presented its *Review of the Human Fertilisation and Embryology Act* to Parliament, noting that “strong ethical concerns remain associated with screening and selection ... of embryos, and about the legitimacy of the choice which may be presented” (Department of Health 2006, 14). It further stated that “[d]eliberately screening-in a disease or disorder will be prohibited” (2006, 14). No explanation or reason was provided for this prohibition and the restriction subsequently appeared within the Human Fertilisation and Embryology Bill. This is surprising, as the House of Commons Science and Technology Committee had noted in its report on human reproductive technologies that whilst “many clinicians would baulk at the idea of selecting ... a deaf child using PGD ... [the Committee did] not feel that the creation of a child with reduced life opportunities is sufficient grounds for regulatory intervention” (House of Commons Science and Technology Committee 2005, 66). Furthermore, and most significantly, it was also observed that there “needs to be further debate” in this area (emphasis added) (2005, 66).

Remarkably, s 14(4) received scant attention during Parliamentary debate, although some limited reference was made to the prohibition. Baroness Deech (former Chair of the HFEA) stated that “I hope that your Lordships will be pleased that the deliberate choice of an embryo, that is, for example, likely to be deaf will be prevented by Clause 14” (HL Deb, Vol 696, col 673, November 19, 2007).

This comment, together with the explicit reference to deafness in the original version of the Explanatory Notes, and the failure of the Department of Health and the Human Genetics Commission to engage the Deaf community in the consultation process surrounding the prohibition, “led to an international campaign by Deaf and hearing people against the clause” (Emery, Middleton, and Turner 2010, 159–160). This was problematic because the failure: to seek the views of Deaf citizens meant that Deaf people – who might predictably object to the singling out of deafness as a “serious illness,” a “physical disability,” or an “abnormal” condition – were not readily available to have their views taken into consideration. (Emery, Middleton, and Turner 2010, 160)

The subsequent lobbying that took place against the prohibition was significant, encompassing radio and television campaigns, articles in newspapers, blogs, online discussion forums, public events and debates, and petitions (Emery, Middleton, and Turner 2010, 161–162). Although these efforts may have resulted in a fuller appreciation of the problematic nature of s 14(4), by this point, the damage was already done; in our view, it was this *process* that problematized the issue.

On 19 March 2008, a meeting was convened between advocates of the Deaf community and representatives of the Department of Health. The meeting was intended to clarify the intention behind the proposed new section and how it would apply to embryo testing and selection in relation to deafness. The subsequent letter (mentioned above) set out the Department of Health's position; embryo testing should only be permitted where the intention is to avoid a serious medical condition, serious illness or disability (Department of Health 2008). The letter acknowledged that many people in the Deaf community do not regard deafness to be a serious medical condition or a disability. Nevertheless, even if deafness is considered to be a positive attribute by an individual couple, according to the Department of Health, it would be inappropriate to use technology such as PGD to select for this attribute. The reasoning underpinning the Department of Health's view, however, is not transparent.

The only reasoning provided during the House of Lords debate, was that of Earle Howe, who stated that “the idea [of selecting for disability] is repellent because it ignores one of the issues central to any IVF procedure, namely, the future welfare of the child” (HL Deb, Vol 698, col 23, January 21, 2008). This could explain why other scholars have analyzed the issue from a liberal perspective where the notion of harm or welfare is a significant factor in the analysis (see Taylor 2010; Wilkinson 2010; Fahmy 2011). Although this is one possible

explanation for the reasoning underpinning the prohibition, this reasoning can and has been challenged by other commentators. In the final part of this paper, we question whether there may be other venues within which this debate may resurface and be given more thorough consideration in the future. Before pursuing this line of enquiry, we consider what is meant by the notion of disability and how this applies in the context of deafness.

## **Defining “disability”**

Disability is a complex and fiercely contested concept. Inconsistent usage and politicization abound, with narratives about “disability” often being fashioned from within competing ideological frameworks. Nevertheless, to begin unpacking this term, we can look to definitions within UK statutes. “Disability” is not defined within the 1990 Act or the 2008 Act. However, a statutory definition can be found within s 6 of the Equality Act 2010, which states that a disability is “a physical or mental impairment” that has a “substantial and long-term adverse effect” on a “person's ability to carry out normal day-to-day activities.” As a matter of administrative practice, deafness falls within this definition. Deaf people are, therefore, given protection from discrimination in fields such as employment and may also receive welfare payments under the Disability Living Allowance scheme. Although some may welcome these legal entitlements, as discussed below, some Deaf people nevertheless reject the idea that they are disabled.

One difficulty with the definition provided above is that it measures disability on the basis of an individual's deviation from “normal” activities. This approach leans toward the “medical model” of disability, which focuses on labeling disability as a biological phenomenon (Karpin and Savell 2012, 15). Although the medical model “remains the dominant mode of thinking about what constitutes disability” (Karpin and Savell 2012, 17) it is problematic for several reasons. First, it neglects the fact that many “[d]isabled people themselves quite naturally reject being defined as abnormal” (Llewellyn and Hogan 2000, 159). This is a view that we consider below, in relation to members of the Deaf community. Second, the medical model seeks to categorize the notion of disability *purely* on the basis of an individual's “biological abnormality.” Importantly, it assumes “that the human being is flexible and ‘alterable’ whilst society is fixed and unalterable. The emphasis is upon adaptation to the environment” (Llewellyn and Hogan 2000, 158). Although the medical model may be a useful starting point for considering the phenomenon of disability in some circumstances, one



of its most problematic aspects is that it overlooks the social context in which the person labeled as “disabled” lives and operates. This model has, therefore, been identified as incomplete (Llewellyn and Hogan 2000, 163).

From the early 1970s, a different notion of disability began to emerge, where disability was determined on the basis of “what [was] labeled socially constructed barriers. This approach has been theoretically elaborated and termed ‘the social model of disability’” (Kermit 2009, 162). As noted by Karpin and Savell, according to this model, “disability can be seen as a form of oppression, an artifact of cultural or socio-political arrangements that disvalue and exclude individuals with impairments” (2012, 18). Like the medical model, however, the social model of disability has also been heavily criticized (see Karpin and Savell 2012, 16–21). Nevertheless, the benefit of the social model is that it seeks to advance the understanding of what is meant by disability in an attempt to foster justice and enable greater inclusion for people with disabilities (Karpin and Savell 2012, 18). The social model of disability features heavily in some of the arguments that we outline below which are often construed to argue why deafness should not be classified as a disability.

Others have considered the difference between the concepts of “disability” and “impairment.” This distinction has been tied to both the medical model and the social model. For an example of the former approach, a definition adopted in a document published by the World Health Organization in 1980 distinguished the two concepts in the following way:

In the context of health experience, an impairment is any loss or abnormality of psychological, physiological, or anatomical structure or function ... a disability is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being. (WHO 1980, 27–28)

In stark contrast, an example of a definition influenced by the social model is provided by the Union of Physically Impaired Against Segregation, an early UK-based disability rights organization, which stated:

Thus we define impairment as lacking part or all of a limb, or having a defective limb, organ or mechanism of the body; and disability as the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from the mainstream of social activities. (Union of the Physically Impaired Against Segregation 1976, 14)

Understandings of what constitutes a “serious disability,” particularly in the contexts of prenatal or preimplantation diagnosis, might also be shaped by the different models. From the medical model perspective, determining the “seriousness” of a condition might turn upon estimating the severity of its likely impact on a child's quality of life. As an example in this vein, the Royal College of Obstetricians and Gynaecologists in the 2010 version of its guidelines, *Termination of Pregnancy for Fetal Abnormality in England Scotland and Wales: Report of a Working Party*, directs doctors to consider the following five criteria:

1. the potential for effective treatment, either in utero or after birth;
2. on the part of the child, the probable degree of self-awareness and of ability to communicate with others;
3. the suffering that would be experienced;
4. the probability of being able to live alone and to be self-supportive as an adult;
5. on the part of society, the extent to which actions performed by individuals without disability that are essential for health would have to be provided by others. (Royal College of Obstetricians and Gynaecologists 2010)

Yet from within the paradigm of the social model, it might be countered that “seriousness” is a social construct influenced by misperceptions about disability, and that with proper social support and a loving home environment, very few conditions would be deemed so serious as to necessitate prenatal or preimplantation screening (Wertz and Knoppers 2002).

Is there a way to advance beyond this impasse? Kermit acknowledges that commentators such as Shakespeare (2006) do not try and establish which of the models is the “truer” one, but instead take the “critical realist position that both ‘natural’ and ‘social’ factors need to be taken into account when approaching the phenomenon of disability” (Kermit 2009, 164). If the realist approach is broadly appropriate, then the problematic issue with s 14(4) is that the different natural and social factors were not taken into consideration when determining that deafness is a serious disability.

We do not seek to argue where deafness *should* fall within the different models of disability (if at all). Instead, we seek to highlight the problematic nature in the uncritical *assumption* that deafness is a serious disability; an assumption that is indeed lingering behind, if not reinforced by, s 14(4). By casting some doubt on the assertion that deafness should be held to constitute a serious disability, we thus aim to show why the lack of engagement with these issues during the reform process was inappropriate. To do this, we

first outline a number of arguments that cast doubt on the claim that deafness is a serious disability, each of which is discussed below.

### **“Deafness is not a disability, but is a culture”**

The Oxford English Dictionary defines a culture as the “ideas, customs, and social behavior of a particular people or society.” Other scholars have applied a similar definition to deafness. Thus, Jones observes that:

Padden and Humphries (1988) [have described] culture as “a set of learned behaviors of a group of people who have their own language, values, rules for behaviors, and traditions” ... They apply this definition to Deaf culture stating that Deaf people behave similarly, use the same language, and share the same beliefs. (2002, 52)

Stern *et al.* reinforce this view, noting that “many deaf people regard deafness and manual communication as distinctive features that define the separate, closely knit culture of the Deaf community” and that “[s]ociologists, linguists, and anthropologists now recognise Deaf people as a special cultural and linguistic population” (2002, 449). The distinction between deafness (with a lower case “d”), and Deafness (with an upper case “D”), stems from the cultural association of those terms (and is an approach we have adopted in this paper). This custom is thought to originate from an article published in 1978 by Markowicz and Woodward (Kermit 2009, 165), where it was stated that:

[t]hroughout this paper we use the convention of capitalizing the word “Deaf” when it refers to any aspect of the Deaf community and its members. Uncapitalized “deaf” refers to the audiological condition of deafness. (1978, 34)

Kermit acknowledges that Markowicz and Woodward were not seeking to argue that there is a gap between these two notions, “but they state a need to distinguish terminologically between *a group sharing a language* and impairment” (emphasis added) (Kermit 2009, 166). This approach also implies, however, that a deaf person (in an audiological sense) who is not an active member of a Deaf community *may* lack a sense of cultural independence in relation to his or her deafness. If this were the case, the argument that deafness constitutes a culture for *all* deaf people is difficult to accept. Nevertheless, there is recognition that Deaf communities do indeed possess their own cultural identity and this is one reason why the term “Deaf” (with a capitalized “D”) has been customarily adopted.

Additionally, as observed by Middleton, Hewison, and Mueller, “[m]any culturally Deaf people are positive and proud to be Deaf” and “have their own language (British sign

language [BSL] in the UK and American sign language [ASL] in the United States)” (1998, 1175). Thus, BSL has its own grammar and syntax, it is the first or preferred language for an estimated 50,000–70,000 people, and was recognized as a minority language by the British Government in 2003 (House of Commons, Written ministerial statement by the Secretary of State for the Home Office, *Hansard*, 31 March 2003). Similarly, many other European Union (EU) Member States have recognized their national sign languages and there are ongoing activities within the EU and at the United Nations, intended to promote and protect sign languages (United Nations General Assembly 2006; European Commission 2013).

On the basis of the above, it seems clear that sign language is a recognized language and that Deaf culture is indeed a culture. This strengthens the view that classifying deafness as a “serious disability” is problematic, as the unquestioned view – contained within s 14(4) – neglects a significant perspective in the debate; the views of Deaf people who live within this unique cultural framework.

Of course, it may be possible for something to be both a culture *and* a disability at the same time. The two categories are not necessarily mutually exclusive. The following sections will, therefore, discuss further the appropriateness of categorizing deafness as a disability.

### **“Deafness is not a disability within the Deaf world”**

Linked to the argument that deafness is a culture and not a disability, is an alternative argument that Deaf people are “disabled more by their transactions with the hearing world than by the pathology of their hearing impairment” (Munoz-Baell and Teresa Ruiz 2000; Bauman 2005). This approach rejects the “medical model” of disability and is instead based on the “social model.”

According to this view, deafness does not constitute a disability within the Deaf world (Bauman 2005). Gallaudet University in Washington, D.C. can be used to illustrate this point. Gallaudet, where McCullough and Duchesneau both studied, is the world's first liberal arts university for the Deaf. Classes are conducted in American Sign Language and English. Many of the Deaf staff, students, and their family live around the campus in a thriving and active community (Parker 2007). Architectural principles known as “DeafSpace,” have been used to facilitate communication and maximize accessibility for Deaf people (Gallaudet Today 2007).

Clearly, deafness is not a barrier to communication within this kind of environment. A Deaf child who grows up in an exclusively Deaf community like Gallaudet may have a perfectly

wonderful and enjoyable life. Nevertheless, that child may one day wish to travel beyond the walled garden of the Deaf community and experience the wider world. It is at this moment that the limiting effects of deafness will become apparent. By contrast, hearing children of deaf adults (CODAs) can potentially move with ease in both the Deaf and hearing worlds. CODAs will, therefore, have a “maximally open future” and a greater range of opportunities than would a Deaf sibling (Levy 2002, 285).

It could be counter-argued that the Deaf struggle in the hearing world is due to the attitudes and lack of abilities of hearing people. If all hearing people were proficient in sign language and knowledgeable about Deaf culture, then interactional difficulties would largely disappear (Sparrow 2005, 137). Such a state of affairs existed, albeit on a relatively small scale, in Martha's Vineyard, Massachusetts, from the eighteenth to the twentieth century (Glover 2006, 6–7). Rates of congenital deafness in Martha's Vineyard were particularly high. Most hearing people learned sign language so they could communicate freely with Deaf family members, neighbors and friends. Deafness was not regarded as being unusual or an obstacle to participation in public life. As Grace observes, these “people were not considered to be (nor did they consider themselves to be) disabled” (2004, 29).

In theory, it would be possible to deploy resources to make sure that all hearing citizens in a country could use sign language (e.g. by making schooling in sign language compulsory until the age of 16). As a policy proposal, however, this is unrealistic and goes far beyond what justice requires of a fair society. Although hearing people may of course learn sign language if they desire, it is difficult to argue that they are morally obligated to do so.

Despite these objections, the view that deafness is not a disability within the Deaf community is one that, at the very least, required consideration during the consultation and reform process of the 2008 Act. Thus, even if it is argued that deafness is capable of constituting a “disability” only in some cases, this in itself may be sufficient ground to cast doubt on the proposal that it constitutes a *serious* disability in all cases.

### **“Deafness is not a limitation”**

Some people argue that deafness does not limit Deaf people's lives. This assertion is embodied in the slogan attributed to the psychologist and former President of Gallaudet University, I. King Jordan: “deaf people can do anything except hear” (Marschark and Spencer 2003, 464). Deaf people can of course do a great many things that hearing people can, such as driving a car, playing sports, using a computer and so on.

Furthermore, in situations where deafness does present barriers, various forms of assistance can expand the range of things that deaf people can do. For example, captioning or in-screen signing can help understanding of television programs, news, and films. Deaf and hearing people can communicate through a sign-language interpreter. Phone calls can be made through systems such as video relay service, whereby a deaf person signs into a video camera viewed by a sign-language interpreter who then translates their signs into speech. Email and text messaging also facilitate communication with the hearing world, and gadgets such as flashing door bells and vibrating alarm clocks can provide signals to deaf people in ways that target senses other than hearing.

Despite these advancements, some may question whether it is correct to say that deafness does not limit people's lives at all. Some of the functional equivalents to hearing can be burdensome and intrusive (e.g. requiring an interpreter for private telephone calls).

Furthermore, even with the use of assistive technologies, there are some things that deaf people simply cannot do. They cannot hear a warning shouted from behind or a cry for help from around a corner. They cannot communicate using sign language in darkness or if the line of sight is obscured. Depending on their degree of deafness, some deaf people may be unable to pass the hearing tests required for certain jobs, such as roles within the police force and the military, or as pilots within commercial airlines (Home Office 2004; Civil Aviation Authority 2010; Ministry of Defence (Army) 2011).

Deafness can also be limiting in a more foundational and global way. It restricts the ability to interact with others in mainstream hearing society. It is harder for Deaf people to participate in spoken conversations, gain useful information and build relationships with hearing people. Deaf people are thus deprived of what has been called a “natural primary good” – a capacity that is useful and valuable for carrying out almost any life plan (Buchanan *et al.* 2000).

The limiting effects of deafness are evident in the domain of education. People who are born deaf or lose their hearing in early childhood may experience great difficulty with speech and their understanding of spoken language. This often brings corresponding problems for literacy, which in turn leads to lower than average levels of educational achievement for Deaf people (National Deaf Children's Society 2008). However, this educational imbalance may represent the fact that historically, most teachers taught in spoken language and Deaf “students often had to strive more to understand what was said, than to understand the curriculum's content” (Kermit 2009, 170).

Employment can present further challenges. Whilst there are a number of successful deaf people working in fields such as medicine, law, science and technology, the arts and music (Toole 1996; Heffernan 2008), the overall picture is less positive. UK statistics indicate that the percentage of deaf people of working age who are employed is approximately 63%, as compared to 75% of the population as a whole (Royal National Institute for Deaf People 2006). It may be argued that this figure reflects structural problems within the education system or widespread prejudice against deaf people (e.g. they are underpinned by social factors). An alternative explanation, however, is that the inability to hear is a genuine disadvantage for professional life. Whichever of these views is true, there is nevertheless the possibility to argue that deafness does not impose limitations upon deaf people in all spheres of life. This in itself casts doubt on the assertion that deafness constitutes a *serious* disability in all contexts.

### **“Deaf people should have the final say on whether deafness is a disability”**

Lane argues that “there is no higher authority on how a group should be regarded than the group themselves” (2005, 298). As Deaf people have lived with the practical implications of deafness every day of their lives, it is perhaps they, and not hearing people, who are best placed to decide on whether it is a disability or not.

This assertion, however, can also be questioned. Whilst congenitally Deaf people of course have extensive knowledge of what deafness entails, others have observed that they are, nevertheless, poorly placed to understand what hearing is like or appreciate the benefits that it can bring to a person's life (Shaw 2008, 411). Mill argued that on questions concerning which of the two modes of existence are better, the “competent judges” are those with experience of both states (1863, 15). Following Mill's suggestion, perhaps significant weight should be given to the views of people who have traveled between the Deaf and hearing worlds by either losing or gaining the ability to hear. Do they view deafness as a disability?

### **Hearing loss**

Views on hearing loss vary. Beethoven, for example, was tormented cruelly by his deafness. In a letter to a friend he wrote:

How humbled I felt when a person standing near me could hear a flute that was playing in the distance, while I could hear nothing! Experiences like this brought me to the very verge of despair, and I came very near to ending my own life. Art alone held me back. (Tremble 1932, 547)

In addition to this kind of narrative, there are also individuals who pass through an initial phase of shock and anger but then achieve gradual acceptance of their condition. Jane Cordell, a former British diplomat who lost her hearing in her 20s, discusses how she eventually came to terms with her deafness:

I think for any major loss like that you go through the sort of grieving process and you're devastated by the loss. Then you feel angry, anger is a significant feeling, you start to adjust and assimilate to the new reality. There's lots of things that you can do, there's hearing aids, there are people out there who can help you, I was lucky to have such a fantastic range of supportive people around me ... but it's actually what's inside you that's most important and how you choose to respond to each situation. (Action on Hearing Loss 2011, 5)

Some people also mention positive aspects to deafness. For example, in his autobiography, Kitto describes his heightened sensitivity to the visual beauty of art and nature (1852, 47). Aaron Williamson reports that at the onset of his deafness, he “consulted with many doctors, and they all told him the same thing. ‘You're losing your hearing.’ He wondered why it was that not a single doctor told him he was *gaining his deafness*” (Bauman and Murray 2009, 3). As noted by Bauman and Murray, this notion of “Deaf Gain” offers a provocative reframing of deafness. Rather than perceiving it as a loss or burden, to some people, deafness may instead be viewed as the gateway to a new language and a rich and valuable culture.

### **Hearing gain**

Recipients of cochlear implants can offer valuable insights into the experience of hearing gain. Cochlear implants convert sounds into electrical signals, which are then sent to the brain via the auditory nerve. They can be helpful for people who have severe or profound hearing loss caused by damage to the cochlear hair cells and who cannot benefit from regular hearing aids. Although cochlear implants do not fully restore hearing, they can provide a useful representation of sound and assist the understanding of speech (National Institute on Deafness and Other Communication Disorders 2011). Dale Oftebro, who lost her hearing as a young child and received an implant in adulthood, describes her experience as follows:

What all the technology and testing don't take into account is the personal and life altering aspects of the gift of sound, the only sense at this point that can be restored. Deafness and hearing loss are not just the loss of sound, they have also been described as a “communication disorder” – which it truly is. Not being able to communicate makes it difficult to make connections with others and build relationships; it can be very isolating. So in addition to the actual gift of hearing comes the blessing of communication, and



enhancement of everyday life. I enjoy what I'm hearing so much, all the household sounds, fountains and the ocean, children's voices, birds twittering, trees rustling, leaves crunching. I continue to be grateful for the ability to hear cars coming, things dropping on the floor, the dog barking to announce someone at the door. And of course there's a lessening of tension and stress in not having to work so hard to hear through lip-reading. (Hearing Loss Web 2007)

It is not entirely certain whether Oftebro's perspective is a typical account of the views of those who are born Deaf (or lose the ability to hear in early life) and then receive cochlear implants. There are, however, significant differences in opinion between Deaf adults as to the legitimacy of cochlear implants, with some forming the view that “implantation is a form of forced normalization” (Kermit 2009, 160).

### **The views of hearing CODAs**

As children who are born with the ability to hear, CODAs do not have the experience of deafness *and* the ability to hear, as they are hearing children. However, they do, nevertheless, have a significant understanding of what it is like to live *with* deafness. As noted by Mand *et al.*, “CODAs have a unique life experience. CODAs experience deafness as a normal part of their family life right from the start, not as a shock in adulthood, as is the case for hearing parents of a deaf child” (2009, 723). Consequently, the views of CODAs concerning deafness and disability provide an important perspective. Mand *et al.* reported that CODAs have a similar view about deafness as those of Deaf adults (2009, 726). Significantly, none of the 66 participants in Mand *et al.*'s study (who were all CODAs over the age of 18), described deafness as a “disability” (45.5% viewed it as a “distinct culture/difference,” whilst 50% considered it fell within both categories) (2009, 726). The views expressed by the participants in this study, led the authors to conclude that their:

findings should sound a note of caution for governments, professional bodies and individuals working to develop frameworks for the appropriate use of emerging genetic technologies. Deafness is not necessarily seen as a limited or unfortunate life by hearing people who know most about it, and attempts to impose or enshrine a negative view of deafness in regulations for reproductive technology will not be welcomed by them. (2009, 727)

We conclude that whilst this range of differing views does not provide a definitive answer on the issue of whether deafness constitutes a disability, it does in fact cast a doubt on the view that deafness constitutes a *serious* disability.

### **Three positions on deafness**

We can therefore summarize that there are a number of different positions that one could adopt when considering deafness:

1. Deafness is an impairment, but not a disability; it can be regarded as a cultural identity (and in some cases, regarded as an ability);
2. Deafness is a disability, but not a serious one (whichever model of disability is adopted); or
3. Deafness is a serious disability (whichever model of disability is adopted).

In considering where deafness should fall within these categories, many people may form the view that it is somewhere between statements one and two. Others, particularly those who are knowledgeable of Deaf culture, may categorize deafness within the first statement. Of course, some may feel that there is some overlap between categories one and two. Others may form the view that deafness should fall within the realms of the third statement. However, the arguments that we have outlined above are at least capable of casting some doubt on the view that deafness should automatically be cast within the third category. The UK Government made an assumption that deafness is a *serious* disability. This approach lacked input from the public (including the Deaf community). In the final part of this paper, we seek to question how the assumption underpinning s 14(4) may be challenged in the coming years.

### **Looking to the future**

It is not clear that there was a practical need to amend the HFE Act 1990 so as to prohibit screening in disability. A request submitted by the authors to the HFEA under the Freedom of Information Act 2000 has revealed that, prior to 2008, the HFEA had not received a single application for a license to carry out PGD for the purpose of selecting in favor of a disability (personal communication, January 21, 2013). Although it could be accepted that the drafting of s 14(4) was laudably intended to address a difficult ethical question that may possibly arise in the future, the manner in which this was achieved has given heightened prominence to perspectives that challenge the hegemonic, “commonsense” view of deafness as a disability. The disconnect between the legal certainty achieved (at least in the case of selecting in favor

of deafness) and the ongoing ethical debate gives a sense that there is dialog that is yet to take place about the divergent views of deafness and their full implications for reproductive decision-making.

So what is the prognosis for the future? We foresee that there are two possible routes by which this underlying debate may again bubble to the surface, thus requiring the perspectives of the Deaf community to be engaged with at a more sophisticated level. The first route would be during a future revision of the HFE Act 1990 (as amended). On this occasion, further discussions may be had as to whether or not deafness is a *serious* disability, with the debate being grounded in some of the perspectives in the academic literature outlined above.

In addition to re-evaluation during future legislative amendments to the 1990 Act, a judicial forum is also conceivable. The second route is a possible challenge to s 14(4) under the European Convention on Human Rights (ECHR), which has been transposed into UK law by virtue of the Human Rights Act 1998. Public bodies and other organizations carrying out public functions are not permitted to violate human rights protected under the ECHR. Judges must also interpret and give effect to legislation in a way that is as far as possible compatible with Convention rights.

If a human rights challenge were launched against s 14(4) HFE Act 2008, it would likely be brought under Article 8 ECHR (right to respect for private and family life), supported by reference to Article 12 (right to marry and to found a family) and Article 14 (prohibition of discrimination). A court would first need to rule on whether the ban on preferring “disabled” donors or embryos engaged the right to respect for private life protected under Article 8(1).

“Private life” is a broad term encompassing, inter alia, aspects of an individual's physical and social identity, including the right to personal autonomy, personal development and to establish and develop relationships with other human beings and the outside world (Pretty v UK 2002, Application no. 2346/02). In the case of Evans v UK 2006 (Application no. 6339/05), Article 8(1) was held to incorporate the right to respect for personal autonomy regarding the decision to become or not become a parent and also with regard to the ability to utilize assisted reproductive technologies in order to have a genetically related child.

Arguably, Article 8(1) could also extend to the right to respect for the decision to select embryos predisposed toward deafness, as deafness is a core feature of Deaf peoples' individual identity and a central aspect of the cultural and linguistic minority to which they belong.

If Article 8(1) were found to be engaged, the UK Government would need to justify its limitation on reproductive decision-making under Article 8(2) of the ECHR. Article 8(2) permits interferences with the right to respect for private life that are: "... in accordance with the law and ... necessary in a democratic society in the interests of ... the protection of health or morals, or for the protection of the rights and freedoms of others." Adjudicating whether an infringing measure is "necessary" and "proportionate" is a value-laden process. The European Court of Human Rights has typically granted member states a wide margin of appreciation in sensitive policy areas such as assisted reproduction and taken a notably cautious approach to fleshing out the extent of human rights protection under Article 8 (Evans v UK 2006). For these reasons, a successful challenge to s 14(4) is far from assured. Nevertheless, if prospective Deaf parents were to challenge the human rights compatibility of the HFE Act 2008, the national courts or the European Court of Human Rights might at least provide a forum where subaltern narratives about Deafness could be expressed and given more serious consideration.

## **Conclusion**

Without adopting a particular normative stance, this article has presented critically some of the academic literature that casts a doubt on the view that deafness is a *serious* disability. We have argued that the UK Government's failure to engage seriously with the perspectives of Deaf people during the legislative process and to offer a more robust justification for its selected policy is unsatisfactory from a procedural perspective. Whilst s 14(4) has brought clarity to domestic law, it has also given greater public prominence to the wide divergence of views about the nature of deafness, thereby stirring up the public debate that was itself overlooked during legislative deliberations. Paradoxically, legal certainty has been achieved at the expense of precipitating a kind of ontological crisis about the nature of deafness. The question of whether deafness is a disability and/or a harm therefore seems, if anything, more unsettled and in need of further evaluation as a result. Two possible routes through which dialog may take place in the future have been sketched above. First, this may occur by way of subsequent revision to the legislation, and second, this may result from possible challenges to the compatibility of the 2008 Act with the right to respect for private and family life set out under Article 8 of the ECHR. Irrespective of how this debate occurs, we form the view that

this dialog is indeed necessary so that the views of Deaf people are better represented in the debate.

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